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University of Southern Denmark
Department of Health
Master of Science in Health (Midwifery)

Submitted June 2020

Social support following perinatal loss

- a cross-sectional investigation of the relationship between social support and parental response to loss

Social støtte efter spædbarnsdød

– en tværsnitsundersøgelse af sammenhængen mellem social støtte og forældres respons på tab

Master's Thesis

**By Helen Sutton,
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Supervisor: Dorte Hvidtjørn, MPH, PhD

”Det erklæres herved på tro og love, at undertegnede egenhændigt og selvstændigt har udformet denne rapport. Alle citater i teksten er markeret som sådanne, og rapporten eller væsentlige dele af den har ikke tidligere været fremlagt i anden bedømmelsessammenhæng.”

Helen Sutton, 2. juni 2020

A handwritten signature in black ink, reading "Helen Sutton". The signature is written in a cursive style with a horizontal line underneath the name.

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Resumé

Spædbarnsdød er uventet og rystende, når kommende forældre rammes af den. Lav børnedødelighed betyder, at forældre tidligere i graviditeten knytter bånd til barnet. Den professionelle tilgang til spædbarnsdød, har gennem tiden udviklet sig, og i dag er den almindelige praksis at tilskynde forældrene til at bevare de bånd, der er knyttet til spædbarnet. Den sociale diskurs afspejler imidlertid ikke dette perspektiv, da forældre oplever, at deres sorg ikke anerkendes. Dette kan have konsekvenser for tilpasningen til tabet.

I denne tværsnitsundersøgelse, blev der udført lineære regressioner for at beregne koefficienter for sammenhængen mellem social støtte og respons på tabet. Data fra det igangværende landsdækkende danske kohortestudie "Livet efter tabet" blev anvendt. Forældre besvarede webbaserede spørgeskemaer indeholdende items, som vedrørte sociodemografiske og obstetriske informationer og psykometriske skalaer.

Respons på tab blev målt med The Two-Track Bereavement Questionnaire (TTBQ), for at inkludere aspekter af de vedvarende bånd til spædbarnet. Associationerne blev undersøgt gennem scores af det fulde TTBQ og TTBQ-subskalaer vedrørende henholdsvis den biopsykosociale funktion og den vedvarende relation til afdøde. Derudover blev forbindelsen mellem social støtte og respons på tab vurderet afhængigt af typer af tab.

Resultaterne viste en statistisk signifikant negativ sammenhæng mellem social støtte og respons på tab. Associationerne blev fundet for den fulde TTBQ-score og TTBQ-subskala-score vedrørende det biopsykosociale aspekt af tabet. Forældre, der mistede deres barn ved foetus mors eller neonatal død, var den eneste gruppe, hvor associationen kunne findes. Begrænsninger, vedrørende risikoen for bias, er afgørende for fortolkningen af resultaterne, hvilke bør gøres med forsigtighed.

Social støtte er vigtig for responset på tab blandt forældre. Dette speciale bidrager til eksisterende viden om faktorer, der har indflydelse på forældre efter tabet af et spædbarn. Yderligere forskning bør vedrøre sammenhænge mellem social støtte og respons på tab i en repræsentativ population, og undersøges individuelt blandt forskellige typer af tab.

Abstract

Perinatal death is unforeseen and devastating when the event strikes. Among other things, low perinatal mortality rates result in parents attaching and tying bonds to the infant early in pregnancy. The professional approach towards perinatal loss has through time developed, and today the common practice, is to encourage the bereaved parents to continue the bonds tied to the infant. However, the social discourse does not reflect this perspective, as bereaved parents experience disenfranchised grief, which potential can have consequences for the adaption to the loss.

In this cross-sectional study, linear regressions were conducted to calculate coefficients for the association between social support and response to the loss. Data was conducted from the ongoing nationwide Danish cohort “Life after the Loss”, where bereaved parents were approached with self-administered questionnaires containing items concerning sociodemographic and obstetrical information and psychometric scales.

The response to loss was measured with the Two-Track Bereavement Questionnaire (TTBQ) to include aspects of the continuing bonds to the infant. The association was investigated through scores of the full TTBQ and TTBQ subscales concerning respectively the biopsychosocial functioning and the ongoing relationship to the infant. Additionally, the association between social support and response to loss was assessed depending on types of loss.

The results revealed a statistically significant negative association between social support and response to loss. The effects were found in the full TTBQ-score and the TTBQ subscale-score concerning the biopsychosocial aspect of the loss. Parents who lost their child due to stillbirth or neonatal death were the only group, where the association was found. Limitations regarding the risk of bias is crucial for the interpretation of the results and should be taken with caution.

Social support is important for the response to loss among bereaved parents. This thesis contributes to existing literature on factors influencing bereaved parents following perinatal loss. Further research should concern associations between social support and response to loss in a representative population and investigated individual for types of loss.

Article draft

In the following, an article, addressed to Death Studies, is presented. Author guidelines are available in appendix 1 and 2.

**Social support following perinatal loss - a cross-sectional investigation
of the relationship between social support and parental response to loss**

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Social support following perinatal loss – a cross-sectional investigation of the relationship between social support and parental response to loss

Abstract

Today the common practice, in management of perinatal death, is to encourage the bereaved parents to continue the bonds, tied to the infant, early in pregnancy. However, the social discourse does not reflect this perspective, as bereaved parents experience disenfranchised grief. In this cross-sectional study, linear regressions were conducted to assess the association between perceived social support and response to the loss. The response to loss was measured with the Two-Track Bereavement Questionnaire to include aspects of the continuing bonds to the infant. The results revealed an association between social support and response to loss among bereaved parents.

Keywords: Perinatal loss; bereaved parents, social support, response to loss, Two-Track Bereavement Questionnaire

Introduction

In Western countries perinatal death is a relatively rare birth outcome, as the number of stillbirths has decreased considerably through the past 30 years (Cousens et al., 2011). Today, the loss of an infant therefore is unforeseen for expecting parents, in western societies. In the case of miscarriage, stillbirth or neonatal death, the loss is devastating, and can lead to intense grief and have negative impact on the mental health among bereaved parents (Burden et al., 2016; Krosch & Shakespeare-Finch, 2017). Simultaneously, with the decrease in stillbirths, the psychosocial management of bereaved parents has developed. Until late 1970s, common practice for health care professionals, was to quickly remove the dead infant after the birth, to avoid harming the parents (Hughes & Riches, 2003).

Since then a culture of individualism, low child mortality rates and new family planning patterns, has led to earlier attachment to the fetus (Kofod & Brinkmann, 2017). Also, prenatal ultrasound sessions allow parents to constitute the fetus as a real baby and invites parents to rehearse their emergent parenting skills and initiate the building of the family album (Kroløkke, 2010). These discursive aspects corresponds with the change in contemporary practice, where parents are now widely encouraged to see and hold their dead child (Davies, 2004). The practice is based upon grief theory that emphasizes that the tie to the deceased should not be relinquished, but maintained as an ongoing relationship (Klass, Silvermann, & Nickman, 1996; S. Rubin, 1981). The change in practice reflects a cultural recognition of the dead infant being a significant loss and acknowledging the importance of parents continuing the bonds tied to the infant. By encouraging the parents to see and hold the body of their infant, the memory-making promote better mental health outcomes following the loss (Kingdon, Givens, O'Donnell, & Turner, 2015).

However, parents, who have suffered a loss of their infant, can experience inadequate social support following the loss. A study by Kofod and Brinkmann (2017) found that bereaved parents experience an ambivalence in their grieving due to the cultural uncertainty of the human status of the child. The public discourse is that the loss of a child in pregnancy, birth or shortly after is not as severe as losing a child, that one has “gotten to know”. Contrary to that view, is the existing practice of care promoting the baby as a real child (Kofod & Brinkmann, 2017). The social discrepancy in the legitimization of grief, after the loss of an infant, may cause disenfranchised grief, which results in more intense response to loss or complicate the grief (C. Malacrida, 1999).

Social support is crucial for the adaption to the loss and diminish the stress that follows the loss (Guldin, 2019, p. 108). However, the discrepancy in social discourse regarding bereaved parents, who have suffered a loss of an infant, calls for a need of mapping the demands for support among bereaved parents.

Many researchers have assessed the response to loss indirectly as expected grief outcomes like depression, anxiety and post traumatic grief disorder, but not the grief response per se, or allowing for the effects on grief from relational bonds tied to the infant. The purpose of this study was to measure the response to grief with the psychometric scale “the Two-Track Bereavement Questionnaire” (TTBQ) (Simon S. Rubin, 2011), in the Danish national cohort of bereaved parents “Life after the loss” (Hvidtjørn et al., 2018). TTBQ was developed in 2009 to integrate perspectives of the relationship to the deceased and biopsychosocial changes into the understanding of the grief process. The questionnaire is based upon the theoretical model “The Two Track Model of Bereavement (TTMoB)” by Rubin et al. (1981), that emphasize the loss being related to the nature, duration and experience of loss for adaptive outcomes. Reorganizing the continuing psychological bond to the deceased, was perceived as being an important

aspect of the adaption to the loss. The theory was consistent with other contemporary perspectives on continuing bonds, but while other studies took the aspects of relationship into account as well as the aspects of biopsychosocial functioning, Rubin et al. conceptualized the experience of loss with more nuanced attention to the relational domain (S. S. Rubin et al., 2009). The two tracks included in the questionnaire refer to the Biopsychosocial functioning following loss (Track I), including factors concerning general biopsychosocial functioning and traumatic perceptions of the loss, and the Ongoing relationship with the Deceased (Track II), including factors concerning relational active grief, the close and positive relationship to the deceased and conflictual relationship to the deceased.

By applying this measurement, the aim was to investigate the hypothesis that social support was associated with the response to loss and differed depending on measuring the effect in the two subscales.

The study was carried out in a nationwide Danish setting including parents who had lost their infant during pregnancy, birth or in the neonatal period.

To my knowledge, no studies have been published with the association between social support and response to loss as an a priori hypothesis. This makes it the first study to assess social support as a primary exposure to investigate its effect on response to loss per se with the Two-Track Bereavement Questionnaire.

Materials and methods

Study design and participants

To investigate the association between social support and response to loss in bereaved parents, data was obtained from the ongoing Danish longitudinal follow-up study by

Hvidtjørn and colleagues “Life after the loss”. The study was based on self-administered questionnaires, containing items concerning sociodemographic, obstetric and information and psychometric scales, to assess grief among parents after the loss of an infant during pregnancy after gestational week 14, birth or in the neonatal period. The data collection started in The Region of Southern Denmark in 2016, expanded to The Central Denmark Region in 2017 and became nationwide including all five regions in Denmark in the summer of 2018. The data, for the present study, were conducted March 10th 2020.

Mothers and partners who had lost an infant by miscarriage, termination of pregnancy due to fetal anomaly (TOPFA) and due to stillbirth or neonatal death were eligible to participate.

Procedures

Participants were approached differently depending on place of residence. In the regions of Southern- and Central Denmark, parents were given verbal and written information about the study before leaving the hospital. Parents who gave their consent to participate received an email with a link to the questionnaire. In the rest of Denmark parents were partly approach at the hospital and partly encouraged to participate through announcements on the webpage of the patient organization “The National Association Perinatal Loss” (Landsforeningen Spædbarnsdød). After signing up with email addresses, parents received information and a questionnaire. The self-administered questionnaires were sent out at three time points: 4-8 weeks, 7 and 13 months after loss. Data from the responses 4-8 weeks and 7 months after loss were applied in this study.

Measures

Outcome variables

The primary outcome measure was the Two-Track Bereavement Questionnaire (TTBQ) which was used to assess parents' response to loss 4-8 weeks and 7 months after the loss. The TTBQ by Rubin et al. (2011) consisted of 70 questions measuring bereaved individuals' response to loss. The construct with examples of items are shown in figure 1.

In Rubin's validation of the questionnaire, the participants were the next of kin to deceased children, partners, parents, siblings, friends and other family. Therefore, questions were not all appropriate for bereaved parents of infant death. Thus, the questionnaire was initially modified, so that 18 inappropriate questions were excluded. Examples of items excluded are: "Our relationship was such that when I think of ____, I usually remember our disagreements" and "during his/her life, ____ was a major source of emotional support for me". Hence the sub-scales "Conflictual Relation to the Deceased" were excluded and only one item remained the sub-scale "Close and Positive Relationship to the Deceased".

The remaining 52 items in English was translated to Danish and back-translated to English by research-workers on the study.

The items were rated on 5-points Likert scales and each item coded from 1-5 (1='agree'; 2='partly agree'; 3='neither agree nor disagree'; 4='partly disagree'; 5='disagree'), including the possibility of choosing 'not relevant'. If 'not relevant' was chosen, the item was excluded from calculation of the score. The scores were calculated as means including all completed items, which resulted in scores 1-5. A higher score indicated a more severe response to loss.

The outcome was primarily measured as a full score consisting of the two sub-scales Biopsychosocial Functioning (Track I) and Ongoing Relationship to the Deceased (Track II) and complementary questions on general functioning. Secondly scores of the respective sub-scales Track I and Track II were measured as secondary outcomes.

Exposure variables

The exposure was defined by the degree of perceived social support reported at 4-8 weeks and 7 months after the loss. The perceived degree of support from 19 various persons, e.g. partner, mother, father, midwife and grief counselling group leader, were measured on a 4-point scale and coded from 1-4 (1=not at all; 2=in some degree; 3=in high degree; 4=in very high degree). A score was measured as a mean of all completed items. If “Not relevant” was reported, the item was excluded from the calculation of the mean. Additionally, the perceived social support was measured as change in social support over time. The variable was defined from the lower quartile of the total score of both social support scores respectively 4-8 weeks (2.61) and 7 months (2.31) after the loss. The categories were persistently good social support (>2.61 4-8 weeks after the loss and >2.31 7 months after the loss), decreasing support (>2.61 4-8 weeks after the loss and <2.31 7 months after the loss) and persistently poor support (<2.61 4-8 weeks after the loss and <2.31 7 months after the loss).

Potential covariates

Covariates were chosen a priori based on existing literature. Selected obstetric and sociodemographic factors were chosen as covariates confounding the association, including type of loss (TOPFA >14 weeks of gestation, spontaneous abortion >14 weeks of gestation and stillbirth > 22 weeks of gestation or neonatal death) and assisted fertility (yes/no), sex (woman/man), if the participant had living children (yes/no) and if the

participant/partner were pregnant again at the time answering the questionnaire (yes/no).

Statistical analysis

After descriptive analyses of outcome-, exposure- and covariates, the association between social support and response to loss 4-8 weeks and 7 months after the loss was estimated using linear regression calculating coefficients with 95 % confidence intervals (CI). The full TTbQ score and TTbQ subscale-scores were assessed as outcome measures.

In secondary analysis, the association between change in social support and response to loss was investigated using linear regression. As a sub-analysis, the association between social support and response to loss were assessed depending on type of loss.

All analyses were performed as crude and adjusted associations. Adjusted models included type of loss, assisted fertility, living children, previous loss and new pregnancy.

Due to dependency of data, as parents of the same infant participated in the study, all analyses were carried out with broad confidence intervals. The remaining model assumptions for linear regression was found acceptable.

Missing values on outcome and exposure variables were excluded in the analyses.

To assess if the TTbQ were applicable on the population of the present study, a Cronbach's alpha was calculated to examine the internal consistency of each sub-scales in the modified TTbQ. The full 52-item questionnaire had a reliability of $\alpha=.93$, Track I $\alpha=.87$ and Track II $\alpha=.91$. Furthermore, a Cronbach's alpha was calculated for each of

the sub-scales underlying Track I and II. General Biopsychosocial Functioning $\alpha=.86$, Traumatic Perception of Loss $\alpha=.75$, The Relational Active Grief $\alpha=.86$ and finally, the General Functioning $\alpha=.71$. All scales had an acceptable reliability.

As type of loss and sex were expected to modify the association between exposure and outcome, the covariates were tested for effect modification. No statistically significance was found on the relationship.

All analyses were conducted using STATA 16.1.

Ethical approval

The approval given by The Danish National Data Protection Agency to the cohort study “Life After the Loss”, was valid for this study (No. 18/15684, October 7, 2014). Data was pseudo anonymized, stored and handled in the secure storage system OPEN Analyse at the Region of South Denmark.

Results

A calculation of the response rate was only possible for the Region of Southern Denmark. Here, 35 % out of all eligible parents were forwarded the questionnaire and out of these, who received it, 55% responded the questionnaire. Consequently, the questionnaire had been sent to 848 parents at the time data for the present study was conducted. A flowchart of inclusion of the participants is shown in Figure 2. The sample for this study, was further restricted to 405 parents as questionnaires answered 13 months after the loss were excluded. The same were parents, who had only answered the first questionnaire, 4-8 months after the loss.

Participants characteristics are reported in Table 1. The descriptive analyses showed a majority of the sample being women. Regarding obstetric characteristics, the

mean length of gestation was 24 weeks, and almost half of the participants had lost their infant to stillbirth or in the neonatal period. When asked if the parents had fertility treatment prior to the pregnancy 22 % confirmed, 6 % had previously lost an infant and more than half of the parents had children before the loss. Almost every parent saw the infant after it had died and 78 % held it.

The mean of perceived social support score varied from 2.92 4-8 weeks after loss to 2.66 7 months after loss. The mean of response to loss (TTBQ) full score, including general questions concerning the loss and the subscales Track I (Biopsychosocial Functioning) and Track II (Ongoing Relationship to the Deceased) was highest 4-8 weeks after the loss and the same was found for both sub-scales Track I and II.

Table 2 reports numbers and frequencies of perceived social support from various relations. Generally, the support decreased during the period from 4-8 weeks to 7 months after the loss. The frequencies of no social support and some degree of social support increased from the first time point to the other, while high degree and very high degree generally decreased. Partner, friends and family, including parents, parents in law and siblings, were relations who provided the highest degree of support. The support seemed to decrease over time, excepting other parents who have lost, grief counselling group leader and other relations who were the only relations, where very high degree of experienced social support increased from the first time point to the second.

Linear regressions were conducted to assess the association between perceived social support and response to loss measured as full TTBQ score, and TTBQ sub-scale scores (Track I and II). In Table 3 coefficients, matching 95 % confidence intervals and p-values for the associations are reported. Crude regression analyses showed no statistically significant associations in any of the analyses. When adjusting for type of loss, sex, living children, assisted fertilization and previous loss, there was found a

statistically significant negative associations between perceived social support and the full TTbQ score. The effect of the association was almost equal 4-8 weeks and 7 months after the loss. The full TTbQ score decreased 0.14 (CI -0.25;-0.02) 4-8 weeks after the loss when the social support score increased with 1 and 7 months after the loss the full TTbQ score decreased 0.13 (CI -0.25;-0.01). When the response to loss was measured in the two subscales, statistically significant results was only found for Track I 4-8 weeks after the loss. The Track I score decreased 0.18 (CI -0.31;-0.05) when the experienced social support score increased with 1 at 4-8 weeks after loss, when adjusted for confounders. A borderline statistically significant association was found for the association 7 months after the loss, where the Track I score decreased 0.12 (CI -0.25;0.002). When measuring the response to loss in the subscale Track II, the results were not statistically significant.

To investigate how change in experiences of social support was associated with response to loss, linear regression was conducted. Persistently good support was applied as the reference group. In table 4 the results of the regression analyses are reported. The adjusted TTbQ full score 7 months after the loss increased with 0.09 (CI -0.20;0.20) if the social support was decreasing over time and 0.23 (CI -0.01;0.47) if the social support was persistently poor. Neither the crude or the adjusted analysis showed statistically significant results on the associations.

Analyses on the association between social support and response to loss depending on type of loss were conducted to investigate if the effect differed between the three types of loss. First the means and standard deviations for experienced social support scores were calculated. These are specified in table 5. The types of loss were categorized in three groups: Termination of pregnancy due to fetal anomaly (TOPFA) ≥ 14 weeks of gestation, spontaneous abortion ≥ 14 weeks of gestation and stillbirth or

neonatal birth. Means were highest 4-8 weeks after the loss for all three groups. The mean was highest for the group that lost their infant to stillbirth or in the neonatal period. And the group with TOPFA had the lowest mean. In Table 6 the results on crude and adjusted regression analyses, performed on the associations depending on the three types of loss, are shown. The analysis showed the strongest effect of social support 7 months after the loss in the group who lost to stillbirth or neonatal death, and this group was the only one where the association were statistically significant when adjusting for sex, living children, previous loss and assisted fertilization.

Discussion

It was found that parents' perception of social support was associated with the response to loss; the more support they received, the better response to loss were found. This association was also found when the response to loss were assessed in the subscale measuring general biopsychosocial functioning (Track I). No association was found when assessing Track II regarding the ongoing relationship with the deceased. The effect of social support was only statistically significant among parents who had stillbirths or neonatal loss.

The relationship between social support and grief reactions or bereavement outcomes have been widely investigated (W. Stroebe, Zech, Stroebe, & Abakoumkin, 2005).

Though it is a widespread assumption that social support is one of the most important mediators for bereavement outcome, no consistence in current literature exists (W. Stroebe et al., 2005). While the majority of the literature investigates other types of loss, such as grief among bereaved spouses, parents of older children or children, who lost their parents, only few studies engage in the effects of social support on grief outcomes

among bereaved parents following perinatal loss.

The social aspect of grief among bereaved parents, who have lost their infant during pregnancy, birth or in the neonatal period, is stated to have particular importance due to absence of social recognition of the loss (Kofod & Brinkmann, 2017; C. Malacrida, 1999). The absence is expressed within all the support system, including immediate and extended families, medical community, helping professions, legal community and workplace. This involve, among many other things, parents experiencing a lack of informational support from health care professionals. Furthermore, when they give birth to a dead infant an absent representation of legitimacy through legal status of the infant, which has implications for bereavement leave (C. Malacrida, 1999). Other persons' verbalization of the parents' loss can undermine their grief and lead to the parents withdrawing socially (Kofod & Brinkmann, 2017).

The results of the present study found an association between social support and response to loss, which can be caused by the disenfranchised grief among the parents.

A trend in results, on the association between social support and response to loss, showed that the effect of social support decreased from the first time-point to the other. However, when analyzing the association depending on the type of loss, the effect of the social support increased over time for the parents who lost their infant to stillbirth or neonatal death. Connecting this finding to the pattern of social support, where descriptive statistics showed that the social support generally seemed to decrease over time, it could be assumed that the consequences of disenfranchised grief increase over time. As the bereaved parents is confronted with more people, as time passes, the diverge reactions and expectations from surroundings affect the parents' response to the loss.

A study assessing social support and bereavement outcomes, found an association between support from the family and decreasing risk of anxiety and depression. For other groups, such as health care professionals and support groups, the association was not found (Cacciatore, Schnebly, & Frøen, 2009). In the present study, the highest degree of social support seemed to be supplied by the immediate family (partner, mother, father, parents in law and siblings) and friends. If it is assumed that the bereaved parents mostly associate with the family and friends 4-8 weeks after the loss and this might be the reason why the effect of social support is lower at the first time-point for stillbirth parents.

Limitations

Although this study had the advantage of a large population and thus the opportunity to provide evidence on associations between perceived social support and response to loss among bereaved parents, there are some limitations that must be kept in mind when evaluating the results.

First the limitations concerning the causal interpretative power in the nature of the study design must be taken into account. In this cross-sectional study, prevalent perceptions of both social support and response to loss were identified at the same time. This means that it is not possible to establish a temporal association between social support and response to loss. While it is possible that social support effects the response to loss, it is equally possible that the response to loss effects the bereaved parents' perceptions of the support received following the loss.

Another limitation of the study was related to selection problems. The descriptive statistics revealed a skewed recruitment of participants according to type of loss in comparison to the total population. The group of parents with stillbirth and neonatal loss were

the most represented in the sample. In the total population the three groups are almost equally divided (Danmarks Statistik, 2018; Eurostat, 2020; Tidlig Graviditet og Abort - klinisk kvalitetsdatabase (TiGrA-KD), 2018). As no analysis on the nonparticipants of the study were carried out, no information exists to assess if the sample was representative for the total population. However, parents who have mental capacity to answer a comprehensive questionnaire could be expected to be more likely to participate than parents who have more complicated grief reactions. Thus the possibility of selection bias here influence the external validity.

Furthermore, selection bias may occur due to the construction of the questionnaire. The parents were asked 7 months after the loss, if they had any need of social support. If they responded, that they had no need of social support, they were not required to answer the items regarding perceptions of social support from the 19 relation. As a consequence, the sample 7 months after the loss is characterised by being different from the one 4-8 weeks after the loss and the associations cannot be compared. The results on the association between change in social support and response to loss might especially be biased by this, and potentially causes the statistically nonsignificant result. This risk of bias is crucial for the conclusion drawn upon the results, as they might not be valid.

Kofod and Brinkmann (2017) stated that parents have experiences of uncertainty and ambivalence in their own and other people's expectations to the appropriate intensity of their grief. As a result, the parents are concerning if they are grieving too much or too little. Given that diffuse norms on how to grieve exist, the reported scores on TTbQ may be affected by the parents' perceptions on what they think they are expected to answer. The uncertainty on how to grieve can go both ways, either grieving too much or too little, thus the potential misclassification would be nondifferential.

The complexity of the grief condition means that multiple variables influence on the response to the loss. Therefore, it is difficult first to identify all potential confounding variables and next to perform analyses without over adjusting the results because of their mutual interactions. The covariates assessed in the multivariate analyses in this study were chosen a priori and delimited by the variables included in the cohort study.

Liberman (1986) emphasizes that social support itself might be confounded by several factor such as event perceptions, access to help and internal resources for general coping effectiveness. When adjusting for this, the association might not be found.

Implications and further research

This study can contribute to the understanding of how bereaved parents are affected by the social discourse. Results revealed an association between social support and response to loss. The association was only present for parents who lost to stillbirth or neonatal death who had the strongest effect 7 months after the loss. The results were restricted by the methodological properties, which means that limited causality and generalizability can be drawn due to the nature of the study design and risk of bias connected to the selection of the study population.

The perspectives discussed in the present study along with existing literature on the subject, emphasizes the complexity of mapping grief. When introducing a psychiatric diagnosis for prolonged grief disorder (WHO, 2019) caution should be taken towards how potential fixed norms a grief diagnosis entails, which may influence the cultural understanding of grief following perinatal loss.

Further research should consist of longitudinal studies examining the association between social support and response to loss in more detailed differentiated types of loss. Furthermore, investigation of changes in social support over time, in a larger population

depending on types of loss will contribute to more nuanced evidence on the needs of bereaved parents.

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I would like to thank all parents, who contributed to the study with their time, experiences and perceptions following the devastating loss of their children. Your unintentional knowledge will contribute to the improved understanding of the needs related to perinatal loss.

Declaration of interest statement

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Tables

Table 1. Frequencies and means on demographic, obstetric and psychometric characteristics of 405 bereaved parents 7 months after loss unless otherwise is stated.

Characteristics	n	%	mean	sd	min	max	Missing values
Sex							6
Women	292	73.18					
Men	107	26.82					
Marital status							6
Single	9	2.26					
Cohabiting/married	390	97.22					
Participant age (years)			31.72	5.10	20	49	8
Length of gestation (weeks)			23.67	8.12			13
Type of loss							19
Termination of pregnancy							
for fetal anomaly ≥ 14 weeks of gestation	118	30.57					
Spontaneous abortion ≥ 14 weeks of gestation	96	24.87					
Stillbirth or neonatal death	172	44.56					
New pregnancy*	127	39.94					
Assisted fertilization	87	21.80					6
Previous loss	23	5.76					6
Living children	208	52.13					6
Saw the dead infant	369	95.10					17
Held the dead infant	286	78.36					40
Participants who reported no need of support 7 months after loss ^a	128	40.25					
Perceived social support score							
4-8 weeks after loss			2.92	0.54	1.35	4	

7 months after loss		2.66	0.54	1.47	4
Change in perceived social support from 4 weeks after loss to 7 months after loss					237
Persistent perception of good social support ^b	113	67.26			
Decreasing perception of social support ^c	31	18.45			
Persistent perception of poor social support ^d	24	14.29			
Response to loss (Two-Track Bereavement Questionnaire (TTBQ)) score					6
Full TTBQ-score ^e					
4-8 weeks after loss		2.69	0.59	1.46	4.16
7 months after loss		2.41	0.58	1.37	4.12
Track I TTBQ score ^f					
4-8 weeks after loss		2.66	0.64	1.18	4.15
7 months after loss		2.49	0.61	1.13	4.05
Track II TTBQ score ^g					
4-8 weeks after loss		2.90	0.83	1	4.75
7 months after loss		2.37	0.80	1	4.75

^aOnly answered at the follow-up questionnaire 7 months after loss (n=318). ^bSocial support score >2.61 4-8 weeks after loss, social support score >2.31 7 months after loss. ^c Social support score >2.61 4-8 weeks after loss, social support score <2.31 7 months after loss. ^d Social support score <2.61 4-8 weeks after loss, social support score <2.31 7 months after loss. ^e Including general questions concerning the loss and the subscales Track I (Biopsychosocial Functioning) and Track II (Ongoing Relationship to the Deceased). ^fIncluding biopsychosocial functioning. ^gIncluding ongoing Relation to the deceased

Table 2. Numbers and frequencies of perceived social support from 19 various relations 4-8 weeks and 7 months after the loss

Relation	Total	None		Some degree		In high degree		In very high degree		Not relevant	
		n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Partner											
4-8 weeks after loss	317	3	(0.95)	5	(1.58)	11	(3.47)	296	(93.38)	2	(0.63)
7 months after loss	270	2	(0.74)	11	(4.09)	34	(12.64)	218	(81.04)	4	(1.49)
Own mother											
4-8 weeks after loss	317	20	(6.31)	45	(14.20)	74	(23.34)	165	(52.05)	13	(4.10)
7 months after loss	270	24	(8.89)	65	(24.07)	63	(23.33)	106	(39.26)	12	(4.44)
Own father											
4-8 weeks after loss	313	33	(10.54)	67	(21.41)	82	(26.20)	103	(32.91)	28	(8.95)
7 months after loss	269	51	(18.96)	93	(34.57)	64	(23.79)	52	(19.33)	9	(3.35)
Parents in law											
4-8 weeks after loss	316	32	(10.13)	84	(26.58)	95	(30.06)	97	(30.70)	8	(2.53)
7 months after loss	269	51	(18.96)	93	(34.57)	64	(23.79)	52	(19.33)	9	(3.35)
Siblings											
4-8 weeks after loss	315	31	(9.84)	80	(25.40)	80	(25.40)	105	(33.33)	19	(6.03)
7 months after loss	269	36	(13.38)	88	(32.71)	67	(24.91)	65	(24.16)	13	(4.83)
Other family											
4-8 weeks after loss	314	46	(14.65)	94	(29.94)	69	(21.97)	63	(20.06)	42	(13.38)
7 months after loss	267	57	(21.35)	91	(34.08)	53	(19.85)	34	(12.73)	32	(11.99)
Friends											
4-8 weeks after loss	317	13	(4.10)	65	(20.50)	113	(35.65)	119	(37.54)	7	(2.21)
7 months after loss	270	10	(3.70)	71	(26.30)	105	(38.89)	81	(30.00)	3	(1.11)
Work colleagues											
4-8 weeks after loss	315	35	(11.11)	96	(30.48)	93	(29.52)	52	(16.51)	39	(12.38)
7 months after loss	267	41	(15.36)	105	(39.33)	58	(21.72)	38	(14.23)	25	(9.36)
Employer											
4-8 weeks after loss	315	43	(13.65)	86	(27.30)	101	(32.06)	56	(17.78)	29	(9.21)
7 months after loss	262	45	(17.18)	83	(31.68)	59	(22.52)	46	(17.56)	29	(11.07)
Other parents who have lost											
4-8 weeks after loss	312	24	(7.69)	50	(16.03)	56	(17.95)	55	(17.63)	127	(40.71)
7 months after loss	269	22	(8.18)	46	(17.10)	60	(22.30)	95	(35.32)	46	(17.10)

Midwife

4-8 weeks after loss	318	7	(2.20)	22	(6.92)	45	(14.15)	234	(73.58)	10	(3.14)
7 months after loss	267	34	(12.73)	49	(18.35)	44	(16.48)	105	(39.33)	35	(13.11)

Doctor

4-8 weeks after loss	318	30	(9.43)	98	(30.82)	99	(31.13)	76	(23.90)	15	(4.72)
7 months after loss	267	29	(10.86)	91	(34.08)	77	(28.84)	56	(20.97)	14	(5.24)

Nurse

4-8 weeks after loss	312	30	(9.62)	57	(18.27)	55	(17.63)	67	(21.47)	103	(33.01)
7 months after loss	265	41	(15.47)	43	(16.23)	45	(16.98)	54	(20.38)	82	(30.94)

Social advisor

4-8 weeks after loss	313	67	(21.41)	7	(2.24)	6	(1.92)	1	(0.32)	232	(74.12)
7 months after loss	265	79	(29.81)	14	(5.28)	3	(1.13)	2	(0.75)	167	(63.02)

Chaplan, imam or other persons

relatet to religion

4-8 weeks after loss	316	35	(11.08)	43	(13.61)	54	(17.09)	62	(19.62)	122	(38.61)
7 months after loss	268	52	(19.40)	40	(14.93)	35	(13.06)	38	(14.18)	103	(38.43)

Undertaker

4-8 weeks after loss	312	37	(11.86)	63	(20.19)	52	(16.67)	52	(16.67)	108	(34.62)
7 months after loss	266	57	(21.43)	56	(21.05)	39	(14.66)	18	(6.77)	96	(36.09)

Advisor from the patient organi-

sation "National Association

Stillbirth"

4-8 weeks after loss	315	38	(12.06)	51	(16.19)	34	(10.79)	32	(10.16)	160	(50.79)
7 months after loss	269	48	(17.84)	35	(13.01)	36	(13.38)	27	(10.04)	123	(45.72)

Grief counselling group leader

4-8 weeks after loss	315	24	(7.62)	35	(11.11)	56	(17.78)	64	(20.32)	136	(43.17)
7 months after loss	254	28	(11.02)	21	(8.27)	33	(12.99)	65	(25.59)	107	(42.13)

Other

4-8 weeks after loss	298	36	(12.08)	35	(11.74)	17	(5.70)	14	(4.70)	196	(65.77)
7 months after loss	256	38	(14.84)	37	(14.45)	28	(10.94)	44	(17.19)	109	(42.58)

Table 3. Associations between perceived social support score and response to loss (Two-Track Bereavement Questionnaire (TTBQ)-score) 4-8 weeks after the loss and perceived social support score and response to loss (TTBQ score) 7 months after the loss.

4-8 weeks after loss					7 months after loss						
Crude					Adjusted ^c						
TTBQ-Score	β ^a	95 % CI ^b	P-value	TTBQ-Score	β ^a	95 % CI ^b	P-value	TTBQ-Score	β ^a	95 % CI ^b	P-value
Full											
TTBQ-score ^d	-0.07	(-0.20;0.06)	0.268	3.08	-0.14	(-0.25;0.02)	0.018	2.68	-0.06	(-0.18;0.07)	0.365
Track I											
TTBQ-score ^e	-0.11	(-0.26;0.03)	0.125	3.15	-0.18	(-0.31;0.05)	0.006	2.77	-0.05	(-0.18;0.08)	0.433
Track II											
TTBQ-score ^f	0.01	(-0.17;0.20)	0.891	3.15	-0.07	(-0.24;0.10)	0.389	2.35	0.06	(-0.11;0.23)	0.457
Regression coefficient. ^b 95 % confidence interval. ^c Adjusted for type of loss, sex, living children, assisted fertilization and previous loss. ^d Including general questions concerning the											

^aRegression coefficient. ^b95 % confidence interval. ^cAdjusted for type of loss, sex, living children, assisted fertilization and previous loss. ^dIncluding general questions concerning the loss and the subscales Track I (Biopsychosocial Functioning) and Track II (Ongoing Relationship with the Deceased). ^eIncluding Biopsychosocial functioning. ^fIncluding Ongoing Relationship to the Deceased

Table 4. Association between change in experience of social support, from 4-8 weeks to 7 months after loss, and response to loss (Two-Track Bereavement Questionnaire (TTBQ)-score) 7 months after the loss.

Change in perceived support	Crude				Adjusted ^c			
	TTBQ-Score	β^a	95 % CI ^b	P-value	TTBQ-Score	β^a	95 % CI ^b	P-value
Persistently good support ^d	2.55	0	ref		2.43	0	ref	
Decreasing social support ^e		-0.08	(-0.31;0.16)	0.514		0.009	(-0.20;0.22)	0.935
Persistently poor social support ^f		0.07	(-0.20;0.33)	0.616		0.23	(-0.01;0.47)	0.063

^aRegression coefficient. ^b95 % confidence interval. ^cAdjusted for type of loss, sex, living children, assisted fertilization and previous loss. ^dexperienced social support score >2.61 4-8 weeks after loss, experienced social support score >2.31 7 months after loss. ^eex-

Table 5. Means and standard deviations (SD) for perceived social support scores 4-8 weeks after loss and 7 months after loss depending on type of loss.

Type of loss	4-8 weeks after the loss					7 months after the loss				
	n	mean	SD	min	max	n	mean	SD	min	max
Termination of pregnancy due to fetal anomaly \geq 14 weeks of gestation	96	2.87	0.56	1.37	4	86	2.58	0.58	1.47	4
Spontaneous abortion \geq 14 weeks of gestation	79	2.93	0.63	1.36	4	55	2.60	0.55	1.62	3.71
Stillbirth or neonatal death	133	2.97	0.47	1.68	4	116	2.76	0.50	1.71	4

Table 6. Associations between experience of social support score 4-8 weeks after the loss and response to loss (Two-Track Bereavement Questionnaire (TTBQ)-score) 4-8 weeks after loss and experience of social support score 7 months after the loss and response to loss (TTBQ score) 7 months after loss, depending on type of loss.

Type of loss	4-8 weeks after the loss					7 month after the loss										
	Crude			Adjusted ^d		Crude			Adjusted ^d							
	TTBQ-score ^a	β^a	95 % CI ^c	P-value	TTBQ-score ^a	β^a	95 % CI ^c	P-value	TTBQ-score ^a	β^a	95 % CI ^c	P-value				
Termination of pregnancy due to fetal anomaly \geq 14 weeks of gestation	2.69	-0.08	(-0.30;0.13)	0.435	2.84	-0.04	(-0.24;0.17)	0.717	2.42	-0.05	(-0.24;0.15)	0.632	2.57	-0.01	(-0.20;0.17)	0.876
Spontaneous abortion \geq 14 weeks of gestation	2.91	-0.06	(-0.28;0.15)	0.578	3.40	-0.16	(-0.38;0.05)	0.137	2.67	-0.04	(-0.30;0.23)	0.772	3.29	-0.15	(-0.42;0.12)	0.278
Stillbirth or neonatal death	3.41	-0.19	(-0.40;0.02)	0.082	3.60	-0.17	(-0.37;0.02)	0.082	3.29	-0.21	(-0.41;-0.02)	0.034	3.60	-0.24	(-0.42;-0.07)	0.008
Full Two-Track bereavement Questionnaire (TTBQ) score, including general questions concerning the loss and the subscales Track I (Biopsychosocial Functioning) and Track II (Ongoing																

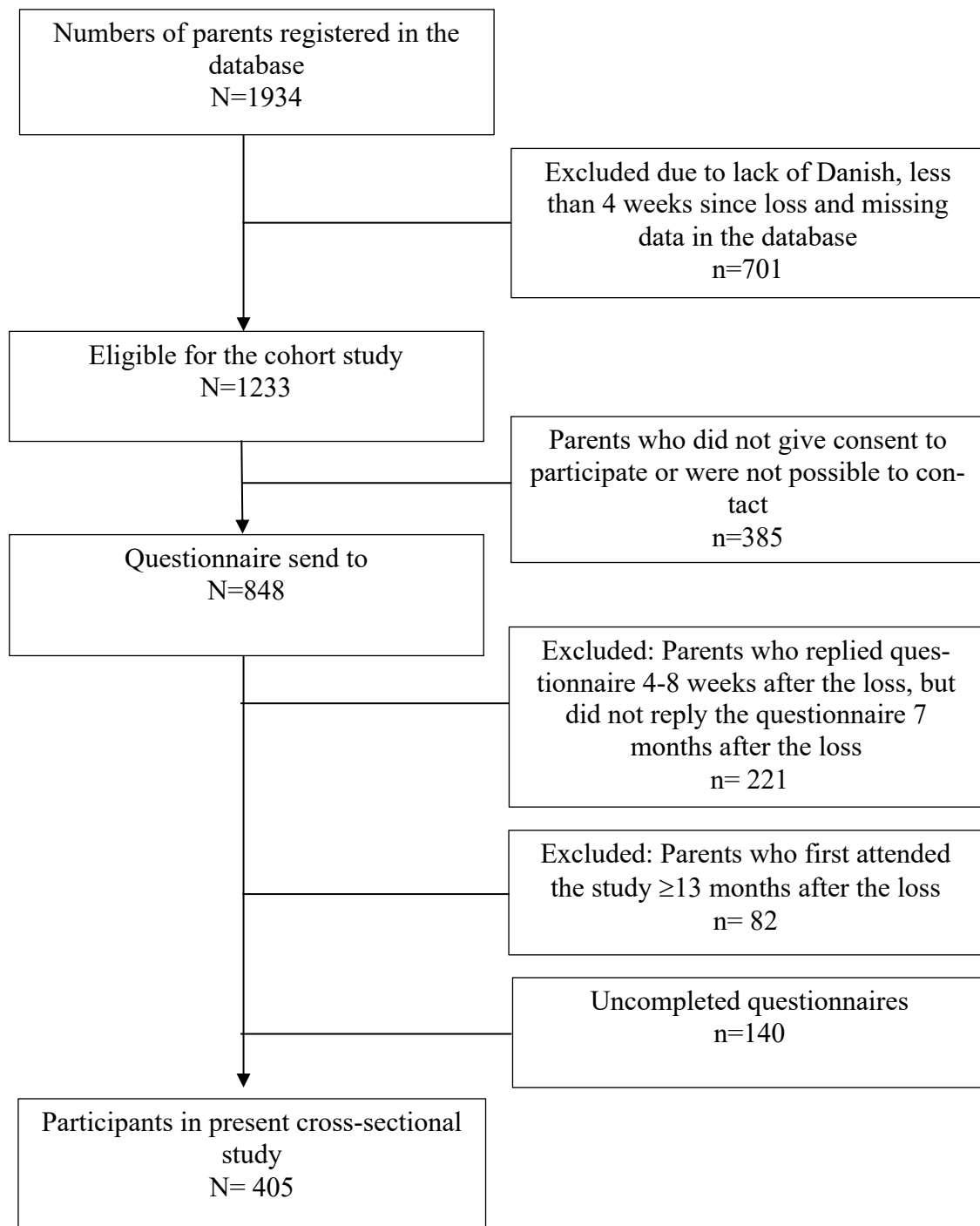
^aFull Two-Track bereavement Questionnaire (TTBQ) score, including general questions concerning the loss and the subscales Track I (Biopsychosocial Functioning) and Track II (Ongoing Relationship with the Deceased) ^bRegression coefficient. ^c95 % confidence intervals. ^dAdjusted for sex, living children, assisted fertilization and previous loss.

Figures

Figure 1. The full Two-Track Bereavement Questionnaire with subscales including factors and examples of items within the subscales.

The full Two-Track Bereavement Questionnaire		
Track I - Biopsychosocial Functioning	Track II - Ongoing Relationship to the Deceased	
General Functioning	Relational Active Grief	General
<i>I believe and trust in my abilities to cope on my own</i>	<i>I am flooded by the thoughts and feelings about the death of ____</i>	<i>Connections with others outside the family are a significant source of support for me</i>
<i>My connections with my close family are close</i>	<i>I yearn strongly for ____ and miss him/her deeply</i>	<i>I find it hard to recall memories of _____ even when I try to</i>
Traumatic perception of loss	Close and Positive Relationship to the Deceased	
	<i>The loss was traumatic for me</i>	
	<i>Overall, my relationship with _____ was based on a sense of mutual trust</i>	
	<i>The relationship between _____ and I was based on mutual understanding, freedom, and a sense of comfort or “flow”</i>	
	Conflictual Relationship to the Deceased	
	<i>My relationship with _____ was characterized by sharp changes between being close to being angry and/or wishing to be distant</i>	
	<i>My relationship with _____ had much avoidance and distance</i>	

Figure 2. Flowchart of the study population



Extended introduction

Scientific theoretical considerations

In the following, I will state the scientific theoretical perspective from which this thesis has its standpoint. The present thesis was based on quantitative data and thus places itself within the natural scientific paradigm.

The modern scientific paradigm was established in the mid-1920s with the positivism as a reaction to the unsystematic and experience-based knowledge in past sciences. Since then, the positivism has been criticized and the prevalent scientific theoretical approach within natural science, is the critical rationalism (Gilje, 2012, p. 51).

The overall ontological framework of critical rationalism is that scientific knowledge should reflect the reality, as it is separated from the senses and thoughts the researcher might have concerning the object (Juul & Pedersen, 2012, pp. 14-15). Thus, the goal, in the present study, was to investigate an association, by quantifying individuals' experiences and perceptions to deduce the relation.

The object of research is tested within a hypothetical-deductive-method, where the hypothesis is established based on existing theory. The central in critical rationalism is that the hypothesis cannot be verified, as no matter how many times an experiment is carried out, the hypothesis can never definitive be verified but solely falsified. If the hypothesis repeatedly has not been falsified, it is considered corroborated (Gilje, 2012, p. 38)

Although the critical rationalism settled with the fallibility of science, it is often a common assumption, that empirical evidence is the golden standard, which is characterized in the contemporary policy of science (Gilje, 2012, p. 61). The academic background of the present thesis is situated in health science. Health research are scientifically rooted, and health care professionals, trained in the post-war era, are brought up in strong confidence in this tradition. The professional environments have gained great power and it is difficult to go against their arguments. It is therefore important to question science and medical practices (Forssén, Hetlevik, & Meland, 2009).

My intention with this thesis has been to investigate the grief per se to contribute to the knowledge of grief reactions, as is normally played out, but I cannot refrain from contributing to a direction that lies within the pathologizing of common grief patterns, as

it is out of my hands how the recipient apply the findings of the study. However, transparency and disclaiming the methodological flaws of the study will be attempted.

Literature review

Grief following loss

Grief is a fundamental emotional state that everyone, at one point in life, will experience (Guldin, 2019, p. 28). Grief has become the subject of scientific interest since Freud in 1917 stated the first hypothesis on grief work. The so-called *grief work hypothesis* emphasized the nature of grief being temporally delimited, divided into phases, and the task during these phases was, for the bereaved person, to relinquish bonds to the deceased (M. Stroebe & Schut, 1999). This classic grief theory has been criticized and developed since then (Guldin, 2019, p. 116) and today *the Dual Process Model of Coping with Bereavement* has become an epoch-making part of grief theory, which have been integrated in research on grief (Guldin, 2019, p. 136).

Grief is defined by Stoebe and Schut (2001/2019) as

The physical and psychological reaction to the loss of someone or something close, to whom or to which emotional bonds have been attached. The reaction involves a wide range of physiological, emotional, cognitive, behavioral and existential symptoms (Guldin, 2019, p. 29).

Grief is the process a person must go through in order to adapt to the loss and learn to live with the life changes the loss has caused (Guldin, 2019, p. 29). In adjusting to the loss, there are various factors that affect the grieving process. The adjustment is contingent on inter- and intrapersonal factors, the circumstances surrounding the loss, the ability to cope, and the grief reaction. The grieving process is a complex interplay between these factors, where, among other things, the prevailing grief culture in society as well as personality, patterns of attachment, cognitive processes, the intensity of grief and social reactions play a role in the adaption to grief (Guldin, 2019, p. 51).

The social support is therefore one factor among many that influence the grieving process. Many studies examining exposures that affect parents' adjustment to grief find that social support is crucial for mental health following infant loss (Cacciatore et al.,

2009; Crawley, Lomax, & Ayers, 2013; Dyregrov & Matthiesen, 1991; Hennegan, Henderson, & Redshaw, 2018; Hughes & Riches, 2003; Hutti, 2005; Swanson, 2000; Vance et al., 1995)

What is social support?

Social support can unfold as information or professional help, which supports the grieving person to adapt to the grief. Furthermore, it appears in the affiliation of a group or family that can perform both practical and emotional support and which helps the bereaved person to overcome the emotional stress the loss may have caused (Guldin, 2019, p. 107).

Both the professional support and the support received from close relations, work colleagues or employer are influenced by the grief culture that is prevailing at the present time (Kofod & Brinkmann, 2017). Grief cultures that appears in cultural, institutional and individual responses, is shaped by sociological factors as religion, technology, institutions, secularization, hierarchies etc. (Walter, 2012). The institutionally facilitation of grief, is reflected in the possibility of grief leave, the provision of a bereavement support group or the arrangement of hospital wards, taking into account the precarious situation it could be for parents to be confronted with living children in a maternity ward (C. Malacrida, 1999).

Historical background on grief culture

Throughout time, the way we mourn has been constantly changing. From a pagan primitive culture of grief before the Middle Ages, to a religiously founded and ritualized grief, to a subdued, introverted and privatized grief culture. Today, the fascination of and attention to grief is more widespread and is an object for cultural and institutional interest and grief culture have become a more extroverted state (Jacobsen, 2020). In 2018 World Health Organization admitted "Prolonged grief disorder" to the list of diagnoses. Since then, the opportunities and challenges this diagnosis provides, have increased an incentive for mapping the scope of grief (Psykologisk Institut, 2020; Remar, 2018). In this thesis I will also engage in the subject.

The rediscovery of grief is evident in cultural and institutional settings. Bereaved individuals express their grief in public with announcements on social media, and memorial events are established as collective grief sessions after terror attacks, or ceremonies to commemorate deceased celebrities beloved by the people (Guldin, 2019).

The extrovert expression of grief also tells in literature, poetry and music where there has been a prosperity in grief literature, with several authors and poets writing both autobiographies and fiction about the subject and are sold as bestsellers (Sørensen, 2017). Through public expression of grief, the individual search for community understanding of the personal loss. The bereaved persons' call for community, changes in grief culture and increased understanding of grief, must be understood as a way of working with death and grief as fundamental conditions of life (Guldin, 2019).

The evolution of the professional management of stillbirth in the health care system

The transformation in grief culture and awareness of death is also seen in the health care systems professionalized and institutionalized attitude to death and illness. The sociologists Glaser and Strauss described in 1965 how health care professionals in different ways approached dying patients and their relatives. They emphasized that dying patients often was not informed or conscious about their imminent death (Jacobsen & Olsen, 2014). The same was apparent in the management of stillbirth in the 1970s, where parents were discouraged from seeing the body of their infant, because contact with the infant was thought to be harmful. The hospital staff took the baby away, organized the cremation or burial in an unmarked grave and parents were advised to put the loss behind them (Hughes & Riches, 2003).

By the late 1970s women begun protesting against the mechanical perspective on childbirth by complaining about the way the body was treated as a component in a mechanical process. Self-awareness and not suppressing one's feelings were encouraged by the women to be an important perspective on management of childbirth (Hughes & Riches, 2003). This movement was also reflected in events of stillbirth, where a more sensitive handling of parents' loss was asked for. The approach received considerable criticism, but despite a lack of systematic evidence, policies were changed to support parents contact with the body of their infant and began to be encouraged to see and hold their baby (Hughes & Riches, 2003). Today the model of care in a Danish setting, is to facilitate the option for the parents to see and hold and make mementoes of the infant and hospital staff must provide human presence and care and give the parents time, information and attendance to understand their loss (Sundhedsstyrelsen, 2013).

Absent social support and its consequences

The change in practice of having contact with the body of the stillborn baby and making mementoes is also reflected in the publication of studies investigating the consequences (Kingdon et al., 2015). In some studies of the association between seeing and holding the body of the baby, the authors find that it did not necessarily appear to be the event of seeing and holding the infant, making memories about it or the rituals associated with it per se, but the opportunity to share the memories with close relations afterwards, that helps parents cope with grief (Crawley et al., 2013; Zhang & Jia, 2020).

The institutional management of parents suffering the loss of their infant, indicate a need from bereaved parents for an acknowledgement of their loss. Studies reveal that parents demand acknowledgement from family and friends of the miscarriage being a valid loss (Meaney, Corcoran, Spillane, & O'Donoghue, 2017; St John & Cooke, 2006) and recognition of the stillborn baby being a real child (Kofod & Brinkmann, 2017).

Unfortunately, several studies have shown that bereaved parents experience an inconsistency in the degree of expected social support and the actual experienced support (Guldin, 2019, p. 110; Kofod & Brinkmann, 2017). The inadequate degree of support can be caused by the relations' hesitated verbalizing the loss because of awkwardness and fear of saying anything appropriate (de Montigny, Beaudet, & Dumas, 1999). The disenfranchised grief, can lead to an increased risk of anxiety and a following demand of therapy afterwards (C. A. Malacrida, 1999). Furthermore, the lack of support can provide an experience of emotional isolation and anger (Rajan, 1994; St John & Cooke, 2006) and the bereaved person can suffer a secondary loss as the persons who were expected to help are also lost (Guldin, 2019, p. 110). The social support is crucial for the adaption to the loss, on one hand because of its ability to complicate the grief response, and cause ongoing effects on interpersonal relationships, and on the other hand, a sufficient support can subsequently ease the transition to a changed life (Guldin, 2019, p. 108) and reinforce the relationship to persons in their network (de Montigny et al., 1999).

Measuring adaption to loss

In several studies, various exposures' effects on bereaved parents' adaption to the loss of their infant has been investigated. Most frequently the outcome measures have been

complicated mental health outcomes following the loss, such as depression (Cacciatore et al., 2009; Crawley et al., 2013; Dyregrov & Matthiesen, 1991; Hennegan et al., 2018; Hughes & Riches, 2003; Hutti, 2005; Swanson, 2000; Vance et al., 1995), anxiety (Cacciatore et al., 2009; Dyregrov & Matthiesen, 1991; Hennegan, Henderson, & Redshaw, 2015; Hughes & Riches, 2003; Hutti, 2005; Vance et al., 1995), post traumatic grief disorder (PTSD) (Crawley et al., 2013; Hennegan et al., 2015, 2018; Hutti, 2005) or independent dysfunctions regarding reactions to grief such as social adjustment problems (Nicol, Tompkins, Campbell, & Syme, 1986). These outcome measures, assess problems with coping indirectly in specific symptoms, but not the grief per se. Through time, various methods have been used to assess grief. The dual process model has a strength being based on empirical research and contains a more nuanced perception on grief, because of its alternation between the emotional and relational bond to the deceased and the functional aspect of grief (Guldin, 2019, p. 128). The psychometric scale applied in the present thesis is *the Two-Track Model of Bereavement Questionnaire* developed by Simon Rubin. By introducing this scale, the aim was, similar to the dual process model, to balance two domains of bereavement: the biopsychosocial functioning and the ongoing relationship to the deceased. Rubin emphasizes, contrary to classical grief theory, that bonds to the deceased, through the grieving process, are transformed and typically will continue for the rest of the life (S. S. Rubin et al., 2009).

The aforementioned importance for bereaved parents being recognized in the dead infant being a real child, makes it relevant to assess the parents' response to grief in a perspective, where the significance of the attachment to the child is considered as important. In a study by Kofod and Brinkman (2017) it was stated, that parents' attachment to their child are initiated earlier in the pregnancy due to society discourse, where, among other things, health technology contributes to low infant mortality rates. In addition, the development in health care technology have involved all expecting parents attending the prenatal diagnostics. As a result, the pictures of the infant initiates the construction of the family album and the attachment to the child (Kroløkke, 2010). These aspects add importance to considering the relation to the dead infant as significant important when assessing bereaved parents' response to loss.

Aim and scope

The aim of this thesis was to assess the association between social support and bereaved parents' response to the loss of their infant. The thesis can contribute to the existing research on how social support influence bereaved parents. Many studies find associations between social support and response to loss as a predictor when investigating other exposures associated with mental health outcomes following loss. To my knowledge no studies have examined the association between social support and response to loss through the scope of the Two-Track Model of Bereavement.

Search strategy

The literature search was conducted from PubMed, as this database contains literature on health science. The focus of the search was based on the research question: Is there an association between social support and response to loss among bereaved parents who lost an infant during pregnancy, birth or in the neonatal period? The query words were defined using the PEO-structure (population, exposure and outcome). For an overview see table 1.

Table 1. Focused query words included in the literature search.

Population	Exposure	Outcome
Parents	Family	Grief
Parental	Friends	Bereavement
Mothers	Societal	Mourning
Fathers		Mourning
	Social support	
And	Support	Adjustment
	Supporting	Response
Perinatal loss		Respond
Neonatal death	Recognition	Responding
Stillbirth	Acknowledgement	Reaction
Miscarriage	Acknowledge	Reactions

The literature search is illustrated in table 2. The first sorting was based on inspection of titles. Non-western articles were excluded, equally was studies with irrelevant titles not engaging in the loss of an infant. Abstracts were read and evaluated of relevance. Studies concerning differences in grief reactions among men and women, experiences of pregnancy following a loss of an infant and health care professionals' experiences of managing perinatal death, were among subjects that was excluded. Finally, two studies was found which concerned the exact research question about the association between social support and parental grief reactions: Cacciatore, Schnebly and Frøen, "The effects of social support on maternal anxiety and depression after stillbirth" and Kofod and Brinman "Grief as a normative phenomenon: The diffuse and ambivalent normativity of infant loss and parental grieving in contemporary Western culture". In figure 1 the selection process is shown.

As sparse literature concerning the research question was found, the topic was found chain search method was carried out throughout the writing process to find suitable literature.

Table 2. Search strategy

Search strategy		
Phase		Numbers of articles
0	Defining the query words	
1	Literature search in PubMed	159
2	Sorting by country	
	Sorting by titles	60
3	Sorting by abstract	
4	Final articles included	2

Extended discussion

In the present study, self-administered questionnaires have been applied to collect data on information about bereaved parents and their perceptions on the loss of an infant. The questionnaires contained psychometric constructs, which have been used to measure the exposure variable, perceived social support, and the outcome variable, response to loss.

In the following I will discuss the conceptual models and the psychometric properties of the exposure and outcome measurements assessed in the study. Measuring interpersonal relationships that affect the mental health of bereaved parents are a challenging task, and a discussion on the sufficiency of the constructs' ability to reflect the perceived social support and response to loss seems important.

The Two-Track Bereavement Questionnaire

The theory behind The Two-Track Bereavement Questionnaire (TTBQ) accentuate the importance of reorganizing the continuing psychological bond to the deceased. Rubin et al. conceptualized the experience of loss with more nuanced attention to the relational domain than other conceptual models (S. S. Rubin et al., 2009). The attention to the aspect of relational grief was considered of importance of the present study. As it was stated in the introduction, the decrease in perinatal death, development in family planning patterns and health technology, result in parents being increasingly attached to the infant early in pregnancy (Kofod & Brinkmann, 2017; Kroløkke, 2010). This discursive change in attachment, indicated that the relational bonds to the infant, are tied earlier in pregnancy and thus the relationship to the infant was expected being a significant dimension of the bereaved parents' loss.

The face validity is the immediate subjective evaluation of the degree to which the construct measures, what it is supposed to (De Vet, Terwee, Mokkink, & Knol, 2011). The evaluation of the immediate validity was uncertain, as the population applied in the validation of TTBQ by Rubin et al. was not clear. The population included in the validation, concerned participants who had lost a child, partner, sibling, friend or other family. It was estimated, that if the parents who had lost a child in Rubin's population, were comparable to the present population, the questionnaire would be valid for measuring the response to loss in the present population. Since the specific age of the children who was lost, was not stated in the validation study by Rubin et al., the assessment of the application of the questionnaire, on the present population, was ambiguous. Rubin et al. assessed the

construct validity of the TTbQ. They found that the kinship differences were highly significant. The ability of the construct to distinguish between kinship among five factors, showed that it was able to comprehend very different types of loss' and thus perinatal loss. The validity of the questionnaire for this population was not further assessed, as the face validity was found acceptable.

In addition to the evaluation of the application of the measurement, the reliability was assessed. The measurement theory allowed for excluding irrelevant items, and as a result, certain items of TTbQ were taken out. This concerned factors regarding pre-loss conflictual relationship with the deceased and items about the close and positive relationship to the deceased.

The full 52-item questionnaire had a reliability of $\alpha=.93$. This was consistent with the original 70-item TTbQ with the reliability of $\alpha=.94$, but since the questionnaire contains a large number of items, the reliability of the full scale did not necessarily reflect the actual reliability. Therefore, a Cronbach's alpha was calculated for the two tracks: Biopsychosocial functioning and Ongoing Relationship to the Deceased. Furthermore, the reliability of each of the two track's sub-scales were calculated. All reliability scores were found acceptable; thus, the applicability of the questionnaire was supported.

Contrary to the expectations, the social support did not affect the ongoing relational aspect of the response to loss. In the following the reason will be discussed.

The aspect of the ongoing relationship to the deceased in TTbQ, concerns the relationship to the deceased and the empty space that is left, when the person is lost (S. S. Rubin et al., 2009). In grief theory, social loneliness and emotional loneliness are distinguished. The social loneliness is associated with the feeling of lack of social contact (Guldin, 2019). This type of loneliness might be present for some bereaved parents if, due to lack of social support, they have withdrawn socially. The emotional loneliness is associated with deprivation, thoughts and feelings about the deceased. No other relation can replace the emotional bond tied to the deceased, but disappointment in lack of emotional support following a loss, can increase the feeling of emotional isolation (Guldin, 2019, pp. 109-110) (Guldin, 2019, p. 109). This loneliness is reflected in the dimension of TTbQ, which deals with the ongoing relationship to the deceased. Questions, in the subscale within track II, concerning the close and positive relationship to the deceased conveys the degree of emotional support, closeness and mutual trust (S.

S. Rubin et al., 2009). Almost all of these items were excluded, due to inappropriacy for the population. Examples of items excluded are: “The relationship between ____ and I was based on mutual understanding, freedom, and a sense of comfort or “flow”” and “Overall, my relationship with _____ was based on a sense of mutual trust”. The aspect of emotional loneliness is therefore not represented in the modified questionnaire. The expected effect of social support would possibly have been reflected in this aspect, but since the items on the aspect were excluded, the association in the track II was not found.

It could be assumed, that rephrasing the items concerning the aspect of close and positive relationship to the deceased, would make it possible to measure the effects of social support on the ongoing relationship. However, this would require a new validation of the questionnaire.

Measurement of social support

The present study’s explanatory measures, identified the presence of perceived social support from 19 persons, including family and friends, work relations, health care professionals, help professionals, other parents who have lost and others. The parents were asked, on a 4-point scale, to which degree they perceived social support from each relation. A mean of the items completed were calculated as a total score, which represented the participants overall perceived degree of social support.

In a commentary Liberman (1986) confronts, using existing studies, the pitfalls of current research on the concept of social support. He emphasizes that the term social support needs to be disaggregated in discrete separate parts, if meaningful conceptual progress should be possible. The norm of current social support research fails, as it relies on questionnaires to quantify the subjective perception and establish a degree of mediation between life conditions and health outcomes. The problem seems to bare an oversimplification of the relationship (Lieberman, 1986).

The quantification of the present individual perception of social support might, according to Lieberman’s arguments, be an oversimplification of the actual experiences of the parents. He states, that people are not necessarily able to define and differentiate the social support they receive and utilize. Furthermore, if not the individual would have categorized the answers, as they are in the questionnaires, themselves, the respond will not reflect the actual perceived degree of social support (Lieberman, 1986). The construct of social support, in this study, might not reflect how the social support actually affected

the participants' response to loss, as the simple construct was generated with the assumption that the participants were able to report the actual perception of social support. Items only included one question for each of the 19 relations, where they were encouraged to estimate the degree of the perceived social support. The items were possibly too few and categories too simple to capture the complexity perceived social support.

When asked directly, about the need for social support, people, even when embedded in support relations, respond that they handled the crisis themselves and did not require or utilize others (Lieberman, 1986). The descriptive analyses revealed that 40% of the participants reported no need of social support. As Lieberman states, this might not be a reflection of the participants not having an actual need of support but reflects the point that they are not able to evaluate their needs and perceptions (Lieberman, 1986).

The measurement of social support was not validated through psychometric studies, and the psychometric properties of the scale is unknown. Liebermann emphasize the importance of measurements of social support being distinct and nuanced. In conclusion, the measurement of social support is not a good reflection of the actual social support. If the construct of this measurement were investigated for validity and reliability, it is not assumed, that the results would be satisfying.

Implications for practice

In the introduction of this extended part of the thesis, I positioned myself and the study within the natural scientific theoretical approach. It was stated, that medical science relies on the natural scientific methods when producing evidence. The cynicism about the relevance of social science, involve social processes increasingly being the subject of quantitative research. I have with this study contributed to the quantification of the psychiatric and social processes and found that the complexity of the social relations is difficult to capture without simplifying the construct.

With a growing dominance in health technology, inflation has escalated into risk diagnoses that limit what is usually found normal and the subjective experience of health is given less importance (Forssén et al., 2009). The forthcoming prolonged grief diagnosis is an example of pathologizing a condition that previously have not been defined, and the event of prolonged grief has been a subjective estimation. The accompanied consequences of the grief diagnosis might be an increased demand of the diagnosis from

bereaved persons. The individuals might feel pressure within the grief culture, where a termination of the grief is expected at the certain defined time point, which follows the grief diagnosis.

For doctors and psychologists, knowledge must be constantly updated and expected to be communicated to patients who demand knowledge that they have learned through family and acquaintances, the media or others, who want treatment that is often medical. This means that other things must be deselected in the meeting with the patient and lead to stress and ethical conflicts (Forssén et al., 2009).

The prevailing dominance of risk diagnoses make it important for researchers to consider how the studies are received and applied among other researchers, in professional practice and among layman. In conclusion, an association between social support and the response to loss was stated, but as the risk of bias was found and the construct of social support having its limits, caution should be taken. The results can be suggestive of possible risk factors, but the limitations in establishing a relationship, further research should be carried out – both quantitative and qualitative, so that the subjective experiences of the health remains important.

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Appendix 1

Author-guidelines for Death Studies

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Appendix 2

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